The Association of Child Condition Severity with Family Functioning and Relationship with Health Care Providers Among Children and Youth with Special Health Care Needs in Alabama

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Mulvihill, BA, Slay-Wingate, M, Altarac, M, Mulvihill, FX, Redden, DT, Telfair, J, Pass, M & Ellis, DE, (2005). The Association of Child Condition Severity with Family Functioning and Relationship with Health Care Providers among Children and Youth with Special Health Care Needs in Alabama, *Maternal and Child Health Journal* 9S (2) S87-S97 DOI: 10.1007/s10995-005-3860-3

Made available courtesy of Springer Verlag: http://dx.doi.org/10.1007/s10995-005-3860-3

Abstract:

Objective: The purpose of the present study is to assess how the severity of a child's condition affects family functioning and the relationship with health care providers among children with special health care needs in Alabama. *Methods*: Using the data from the National Survey of Children with Special Health Care Needs (CSHCN), three variables were used as measures of condition severity: responses to the CSHCN screener questions, whether condition affected the ability to do things for children and youth with special health care needs (CYSHCN), and the level of severity of CYSHCN's condition. The dependent variables included family functioning and provider relationship. *Results*: CYSHCN who only take prescription medicine for their chronic condition (MO) had lower condition severity from those who have other needs (NMO). In NMO CYSHCN, higher condition severity was associated with increased strain on family functioning outcomes and higher unmet needs in provider relationship outcomes, adjusted for demographic and insurance variables. Families of NMO CYSHCN with a more severe condition spent more temporal and financial resources and had a higher need for professional care coordination, and were less likely to have sensitive providers. *Conclusions*: Severity of condition is an important factor increasing strain on family resources and relationship with the provider. Our results indicate the need for professional care coordination and family support, particularly among those families in which there is a NMO CYSHCN with a more severe condition. This finding supports the mandate that all CYSHCN should have their health care coordinated and provided in the context of a medical home.

Keywords: children and youth with special health care needs; child condition severity; family functioning; relationship with health care providers.

Article:

INTRODUCTION

Various agencies, groups, and researchers have developed definitions of what constitutes childhood disability, chronic conditions, and ongoing health problems (1–4) and tools to measure them (5–8). These definitions have been applied in various ways to attempt to define children and youth with special health care needs (CYSHCN), to detect the prevalence and to plan appropriate supports and services for the children and youth and their families. As a result of consensus reached regarding characteristics of the population that constitutes CYSHCN, screening questionnaires have been developed to identify a broad group of CYSHCN and have been used in numerous studies (9–11). Further, it has been shown that positive responses to multiple components of screening instruments may identify children and youth with more severe conditions compared to those who responded positively to only one component or question (2).

The severity of chronic condition is not an absolute concept nor is it easily measured, as the severity differs across conditions and ages (12). Severity refers to diverse concepts including biological cause, the amount of disability, the condition's impact on the quality of life, and the financial, social, or emotional impact that the condition plays in the life of an individual or his/her family. Stein et al. characterized one aspect of severity in terms of the impact of the disease or condition on the family or society and called it the burden of illness (13). Newacheck and Taylor later used the data from the 1988 National Health Interview Survey to illustrate the uneven burden of childhood chronic illness demonstrating that chronic conditions are not uncommon among children and youth, but a comparatively small number, around 5%, are severely affected by them (14). A framework of severity surrounding chronic conditions is necessary to provide some structured explanation of the relationship among these concepts (13).

Information about characteristics of and challenges faced by CYSHCN and their families is available from large national population-based studies (15–17), as well as from studies with small sample sizes that are typically difficult to generalize to other populations (18, 19). Little is known about the specifics of CYSCHN and their families at the state level. To address the need for such information, the National Survey of Children with Special Health Care Needs (CSHCN) was developed as a unique population-based instrument designed to yield such state-level data.

The purpose of the present study is to assess the relationship between the severity of a child's condition, family functioning, and the relationship with health care providers among CYSHCN in Alabama, using the data from the National Survey of CSHCN. Our study was guided by the conceptual model advocated by Stein and others that includes physical, functional, and ecological characteristics surrounding the child and his/her family (13).

The present study's underlying hypothesis is that among CYSHCN in Alabama, the severity of a child's condition is related to family functioning and the relationship with health care providers, controlling for demographic and insurance characteristics of the child and family. To address the hypothesis, three research questions guided the study:

1. Does the group of CYSHCN who only take prescription medicine for their ongoing condition significantly differ from those CYSHCN who have conditions other than those requiring medicine only, i.e., do CYSHCN in the medication-only (MO) group have less severe condition compared to other CYSHCN?
2. Is the severity of the child's condition related to differences in family functioning and the relationship with the child or youth's health care provider?
3. Do the differences observed between the severity of the child's condition and family functioning and the family's relationship with the provider remain after adjusting for demographic and insurance factors?

METHODS

The National Survey of CSHCN was conducted as a module of the State and Local Area Integrated Telephone Survey (SLAITS) in 2001 (20). One goal of the National Survey of CSHCN was to obtain state-specific sample sizes that were sufficiently large to permit accurate estimates of the characteristics of CYSHCN in each state. State samples were designed to obtain 750 completed interviews of families of CYSHCN. Interviews were sought from the person most knowledgeable about the CYSHCN, usually the parent. From the national sample, we selected children and youth residing in Alabama, identified by screener questions as having special health care needs (n = 749). More detailed information regarding the SLAITS data and methodology are available elsewhere (20).

Measures

Based upon the work of Stein and her colleagues (3,10,13), the term condition is used broadly to mean the state of health and includes, but is not limited to, illness, impairment, disability, or other health-related issues and their consequences. One way condition severity is measured using this framework is by the number of

consequences experienced because of the condition (10). Different consequences and differing numbers of consequences may be indicators of the severity of the condition.

The Foundation for Accountability's CSHCN screener questions (21) were used to determine the number of consequences that a child experienced or was expected to experience for 12 months or longer. Following from Stein *et al.*'s (10) rationale, we assumed that the severity of the child or youth's condition can be measured by the number of positive responses to the screener questions and that those who only took medication for a chronic condition were likely to have less severe conditions compared to other CYSHCN. Based on these assumptions, we classified the children and youth into two groups. The first group were those who were taking medication for 12 months or longer with no other screener question receiving a positive response (MO group, $n = 332$). For the second group we included everyone else, i.e., those who responded yes to any other question, alone or in combination with the medication question (non-medication-only (NMO) group, $n = 417$). The variables for this study are shown in Table I.

Condition severity was measured by three variables: number of responses to the screener questions (summary score); and two variables of condition perception: the amount of time CYSHCN's condition affected their ability to do things, and the level of severity of CYSHCN's condition. Based on responses to the screener questions, a summary score of condition severity was calculated as a sum of positive answers and was coded 1–4 (4 included those who answered yes to four or five of the questions). The first condition perception variable allowed the respondent to assess the amount of time the children's or youths' condition affected their ability to do things other children their age did in the past 12 months, with choices being always, usually, sometimes, or never. We dichotomized this variable to never versus ever, which included sometimes, usually, or always. The second condition perception variable allowed the respondent to rank the level of severity of the child or youth's condition from 0 to 10, with 0 being the least severe and 10 being the most severe. We recoded this variable into three categories: low (0–3), moderate (4–7), and high (8–10) severity of the child's condition.

Family functioning includes the provision of health care at home, the hours per week spent providing or arranging for care, and the financial burdens that health care placed on the family (see Table I).

Provider relationship includes information about usual source of care, unmet need for care, and parental perception of the care, as related to the amount and quality of the time the medical care provider spent with the family (see Table I).

Statistical Analysis

We calculated descriptive statistics using weight adjusted χ^2 tests for the MO and the NMO group by demographic, condition severity, family functioning, and provider relationship variables.

Bivariate associations were estimated using weight adjusted χ^2 tests by examining whether condition severity was associated with the family functioning and provider relationships. For demographic and insurance variables, if the χ^2 significance was $p \leq 0.10$ at the bivariate level, the variable was included in the adjusted logistic regression models. All the logistic regression models were controlled for child age, child gender, child race, maternal education, family poverty level, child being uninsured within the past year, and the type of insurance (private or other). All analyses were conducted using the SUDAAN 8.0.2 to account for the stratified sampling frame of the study (22). For all subgroups analyses, we followed the recommendations for the appropriate use of sampling weights and the SUBPOPN statement was used to analyze only the NMO group, as described in the technical manual for the dataset (20).

RESULTS

In the sample of CYSHCN in Alabama in 2001, 418 (57%) respondents reported that the children's or youths' condition affected their ability to do things other children their age did sometimes to always in the past 12 months. The ranked level of severity of the child or youth's condition indicated that 331 (45%) were in the low

severity group, 309 (42%) in the moderate, and 99 (13%) in the high. Additionally, 326 (44%) answered positively to two or more screener questions.

We observed significant differences between the families of children who answered yes only to the question regarding whether medication was needed for 12 months or more (MO group) and those with positive responses to one or more other questions in addition to or separate from the medicine question (NMO group) (Table I). Many demographic variables were similar for each group, but they differed on key condition severity characteristics, thus providing evidence that the MO group had lower condition severity, as measured by our study. Many more parents of the MO group perceived their child as never affected by the condition (65 % vs. 21 % of the parents of the NMO group, $p \leq 0.01$). Similarly, 62 % of parents of the MO group rated the condition severity as low as compared to 27% of the parents of the NMO group ($p \leq 0.01$). In this paper, we report results for the NMO group ($n = 417$) because this is the group with higher condition severity, as measured in this study, and is clearly distinct from the MO group. The results for the MO group will be reported separately in a subsequent paper.

Next we examined the severity of condition by family functioning variables (Table II). Among those children who were identified as ever affected by their condition, the burden on the family resources was significantly higher compared to the never group. A monotonic increase (from low to high) across the severity ranking groups was also observed for most family functioning variables, though only one variable, spent 1 or more hours per week arranging or coordinating care, was significantly related to the rankings ($p \leq 0.05$). Summary scores of condition severity were significantly related to all family functioning variables, suggesting that the higher the score, the more resources the family spent or needed.

With regard to provider relationship (Table III), when comparing CYSHCN identified as ever being affected to those never affected by their condition, the ever affected needed more professional care coordination (15% vs. 5%), experienced more delayed care over the past 12 months (17% vs. 4%) and more frequently reported that their doctors never or sometimes listened carefully (19% vs.7%). A monotonic increase (from low to high) across the severity ranking groups was also observed for several provider relationship variables. The need for professional care coordination increased with higher severity rank (3 % for low, 12 % for moderate, and 27% for high; $p \leq 0.05$), as well as provider being never or sometimes sensitive to family's values and customs (8%, 16%, and 33%, respectively; $p \leq 0.05$) and provider never or sometimes helping the respondent feel like a partner (6%, 19%, and 19%, respectively; $p = 0.05$). Two provider relationships variables showed a statistically significant relationship with the summary score of condition severity, not having a personal doctor or nurse and the need for professional care coordination, but the relationships were not monotonic.

The results of the adjusted logistic regression models for the relationship between each measure of condition severity and measures of family functioning and provider relationship are presented in Table IV. Results were consistent with bivariate relationships observed. Adjusted for demographic and insurance variables, CYSHCN whose condition ever affected them had increased odds of the family providing health care at home (OR = 2.5, 95% CI 1.3–4.6), providing care for >1 h/week (OR = 4.3, 95% CI 2.1–8.8), spending >1 h/week arranging care (OR = 4.1, 95 % CI 2.1–7.9), incurring financial problems caused by health problems (OR = 4.7, 95% CI 2.0–11.1), cutting work hours (OR = 4.2, 95% CI 2.0–8.9), needing additional income (OR = 4.8, 95 % CI 2.0–11.6), and stopping work (OR = 6.7, 95 % CI 2.0–22.9). A similar pattern with regard to family functioning variables was observed in the adjusted logistic regression model for the summary score. Adjusted logistic regression models for the condition perception severity rank variable and family functioning outcomes were not statistically significant, but the ORs in these models are in the expected direction. Compared to those who were not affected, the CYSHCN whose condition ever affected them had four times the odds of needing professional care coordination (95% CI 1.4–11.7), adjusted for demographic and insurance variables. Compared with low rank of severity of condition, CYSHCN ranked as moderate and high had significantly higher odds of needing professional care coordination, as did CYSHCN whose summary score was 4, compared with those whose summary score was 1. Additionally, the CYSHCN whose condition ever affected their ability to do things had increased odds of having delayed care in the past 12 months (OR = 7.4, 95 % CI 1.4–39.6), compared to those

who were not affected by their condition. Compared with a low rank of severity of condition, CYSHCN whose condition was ranked as moderate and severe had higher odds of having a provider who was never or sometimes sensitive to the family's values and customs, and of feeling that their provider never or sometimes helped them feel like a partner in care for the CYSHCN.

Table I. Comparison of Children and Youth Who Were Taking Medicines On (MO) and Those Children With Other Conditions, in Addition to or Separa From Those That Require Medication Only (NMO) in Alabama in 2001, b Demographic, Disease Severity, Family Functioning, and Provider Relationship

	% MO ($N = 332$)	% NMO ($N = 417$
Demographic characteristics		
Age of child (categories)		
0–3 years	12.22	13.39
4–6 years	17.18	12.35
7–12 years	44.25	42.47
13–17 years	26.35	31.8
Respondent's relationship to child*		
Mother	84.46	76.51
Father	10.44	10.23
Other relative	5.1	13.26
Child gender		
Male	56.87	65.35
Female	43.13	34.65
Race of child*		
White	70.41	62.53
Black	23.97	35.43
Multiracial	4.65	1.39
Other	0.97	0.65
Maternal education		
Eighth grade or less	2.19	1.79
Some high school	15.93	23.18
High school diploma	28.29	32.47
Post high school, no degree	34.5	27.88
4-year degree or beyond	19.09	14.68
Insurance		
Insured for the entire year	90.18	86.68
Private insurance**	62.81	46.33
Other insurance (Medicaid, Title V, SCHIP, etc.)**	37.19	53.67
Poverty level*		
Less than 100% of FPL	19.85	27.36
100–185% of FPL	14.76	21.23
200–400% of FPL	42.51	33.43
Above 400% of FPL	22.88	17.99
Condition severity		
Summary score of condition severity (screener questions)		
Needs prescription medicines	100	69.51
Needs medical care/mental health/education		75.53
Limited ability to do things		29.12
Needs physical/occupational/speech therapy		19.08
Emotional/developmental/behavioral problem		43.2
Parental perception		
Past 12 months, amount of time child affected by the condition**		
Never	64.99	20.87
Ever (sometimes, usually, always)	35.01	79.13
Severity of child's condition (on scale of 0–10)**		
Low (0–3)	62.41	26.8
Moderate (4–7)	32.55	49.71
High (8–10)	5.04	23.49

Table I. Continued

	% MO ($N = 332$)	% NMO ($N = 417$)
Family functioning		
Family provides health care at home*	50.16	60.91
Number of hours per week spent providing care*		
1 or more hours	30.45	42.52
Number of hours per week spent arranging/coordinating care**		
Less than 1 h	59.48	40.28
Health has caused financial problems**	12.99	31.45
Cut work hours to care for child**	13.09	37.22
Need additional income for child's medical expenses**	11.9	34.21
Family member stopped working/child's health**	4.94	21.37
Money paid for health care**		
$1001+	2.89	13.02
Provider relationship		
Child does not have personal doctor or nurse	5.73	10.26
Child does not have usual source of health	4.88	4.61
Past 12 months, child's health care has been delayed or foregone*	2.72	14.15
Need professional care coordination*	5.76	12.95
Past 12 months, how often did the health care provider spend enough time?		
Never/sometimes	16.59	20.26
Health care provider listened*		
Never/sometimes	8.12	16.14
Provider sensitive to family's values/customs		
Never/sometimes	12.43	18.77
Enough information from the health care provider*		
Never/sometimes	11.91	20.65
Health care provider helps respondent feel like a partner		
Never/sometimes	10.6	15.62

*p-value < 0.05.
**p-value < 0.01.

DISCUSSION

We hypothesized that the NMO group would experience more severe conditions compared to MO group. Our results support this hypothesis, and show that many more parents of the NMO group children perceived their child's condition as affecting them more and being more severe, compared with parents from MO group. Further, more children in the NMO group live in poverty, have higher disease severity scores, live in families where care is provided at home, and experience delayed or foregone care, compared with children in MO group. These findings support long standing beliefs by those in the CYSHCN community and among staff in Alabama's Title V CSHCN program that special attention needs to be paid to children with more complex and severe conditions who are at greater risk for exacerbated social, psychological, and medical morbidity. While the trend has clearly been to move to broader more noncategorical methods of defining CYSHCN (1, 3), these results also raise questions about policy and planning implications that might differentiate between and among groups with different needs based on the level of severity of the child or youth's condition as opposed to a diagnosis-based approach.

In our study, 79% of the respondents said their NMO child or youth was ever affected by the condition over the past year. In NMO CYSHCN, higher condition severity was associated with increased strain on family resources and higher unmet needs in provider relationship outcomes even after we controlled for individual and family factors such as race, age, gender, family poverty level, maternal education, and insurance variables. Our findings are consistent with a previously reported association between family demographic characteristics and family functioning and provider relationship (6, 18, 23). Families of NMO CYSHCN with a more severe condition spent more temporal and financial resources and had a higher need for professional care coordination,

Table II. Severity of CYSHCN's Condition, as Measured by the Amount of Time Their Condition Affected Their Ability to Do Things Other Children Their Age Do in the Past 12 Months, by Family Functioning

	The amount of time child was affected		Severity of CYSHCN's condition (on scale of 0–10)			Summary score of condition severity			
	Never ($n = 100$)	Ever ($n = 315$)	Low (0–3) ($n = 114$)	Moderate (4–7) ($n = 214$)	High (8–10) ($n = 86$)	1 ($n = 82$)	2 ($n = 181$)	3 ($n = 105$)	4 or 5 ($n = 49$)
Family functioning									
Family provides health care at home	51.70	63.32	62.59	61.56	57.81	31.08	66.43	68.16	70.51**
Number of hours per week spent providing care									
1 or more hours	20.71	48.17**	33.51	45.22	47.05	23.54	41.40	47.99	63.18*
Number of hours per week spent arranging/coordinating care									
1 h or more	35.94	65.92**	47.07	64.13	66.46*	48.49	56.33	62.99	80.42*
Health has caused financial problems	13.88	35.87**	27.51	29.21	40.81	18.95	29.82	37.40	42.55
Cut work hours to care for child	18.50	42.54**	33.65	34.11	48.55	14.11	37.90	35.47	70.36**
Need additional income for child's medical expenses	14.77	39.14**	23.69	35.91	43.57	27.04	28.10	32.53	66.08*
Family member stopped working due to child's health	7.54	25.21**	14.50	21.61	29.32	12.56	15.36	20.29	54.31*
Money paid for health care									
$1001+	8.00	14.14	9.38	13.32	17.58	4.67	9.62	17.77	27.72*

*$p < 0.05$.
**$p < 0.01$.

and were less likely to have sensitive providers, who listened, and who made them feel like a partner in their child's care. Our results suggest that, at least for those families who indicated their NMO CYSHCN had more severe conditions in Alabama, professional care coordination is an important unmet need. Receiving effective care coordination is a problem across the nation, according to the national findings from the National Survey of CSHCN (24). Also, it has been documented that a small percent of CYSHCN use most of the health care dollars and services (25), and this study also shows that the families with a CYSHCN whose condition is the most severe, as measured in our study, are also experiencing a higher drain on their family resources.

While this study is population-based, and the results can be applied to the NMO CYSCN in the state of Alabama, there are several limitations. The CSHCN Screener questions are designed to be a more objective and consistent way of identifying CSHCN, but they still rely on the respondent to provide the information as opposed to clinical or record review information. The summary score derived from the CSHCN screener questions does not weight each of the items in terms of its potential importance individually or in relation to each other. We assumed that each of the items contributed evenly to the final severity score for each child. The other two condition severity measures were entirely based on the respondents' perception of the amount of time the child was affected by the condition over the past year and their rating of the severity of the child or youth's condition. Such self-reported data are always suspect and can have questionable reliability. On the other hand, subjective interpretation of the meaning that childhood conditions holds for parents has been found to be an important predictor of family impact of the condition (5). In addition, even though the measures of family functioning are less comprehensive than some used in previous studies (18), our results show a strong association between condition severity and increased demand on family resources.

Sample size is another consideration in applying the results of this study. Many of our 95 % confidence intervals were very wide and though they clearly indicate the direction of the association, the magnitude of the association cannot be discerned. However, the relationships we are reporting here were not previously available for our state and can easily be replicated in other states by using state-specific data from the National Survey of CSHCN.

The Title V funded CSHCN program in Alabama, Children's Rehabilitation Service (CRS), has historically used a categorical approach for service delivery, establishing eligibility for services based on specified diagnostic codes (or clinically diagnosed chronic conditions and disabilities). The CRS program has found it challenging to assess the needs of the broader population of CYSHCN that are not directly served by it.

Table III. Severity of CYSHCN's Condition, as Measured by the Amount of Time Their Condition Affected Their Ability to Do Things Other Children Their Age Do in the Past 12 Months, by Provider Relationship

	The amount of time child was affected		Severity of CYSHCN's condition (on scale of 0–10)			Summary score of condition severity			
Provider relationship	Never (n =100)	Ever (n = 315)	Low (0–3) (n = 114)	Moderate (4–7) (n = 214)	High (8–10) (n = 86)	1 (n = 82)	2 (n = 181)	3 (n = 105)	4 or 5 (n = 49)
Child does not have: personal doctor or nurse	10.41	10.05	7.75	11.97	9.87	21.86	8.71	4.42	10.87*
Usual source of health care	3.80	4.85	2.29	6.14	4.15	4.46	5.21	1.95	7.78
Need professional care coordination	4.49	15.29*	2.96	11.75	27.23*	8.37	8.09	15.93	29.32*
Past 12 months, child's health care has been delayed or foregone	4.28	16.85**	14.33	14.79	12.17	21.73	9.66	13.31	19.55
In the past 12 months, how often did the provider spend enough time?									
Never/sometimes	17.02	21.26	18.96	20.86	21.00	28.55	17.10	16.65	26.58
Health care provider listened									
Never/sometimes	6.89	18.68*	16.40	13.22	22.35	18.64	12.88	16.92	22.01
Provider sensitive to family's values/customs									
Never/sometimes	12.66	20.53	7.66	15.58	32.52*	31.80	12.33	18.17	24.10
Enough info from the health care provider									
Never/sometimes	16.47	21.66	14.15	24.25	20.92	21.01	18.85	20.83	25.65
Providers help respondent feel like a partner									
Never/sometimes	10.78	17.01	6.22	18.72	19.09*	26.66	10.54	15.32	18.57

*$p < 0.05$.
**$p < 0.01$.

Table IV. Adjusted Odds Ratios and 95% Confidence Intervals for Selected Condition Severity Variables, Family Functioning, and Provider Relationship Variables

	Family functioning								Provider relationship					
	Family provided health care at home	Spent >1h/ week providing care	Spent more than 1 h/week arranging care	Health caused financial problems	Cut work hours to care for child	Need additional income	Stopped working	Paid >$1000 for health care in past year	Child does not have a personal doctor or nurse	Past 12 months, child's care delayed	Need professional care coordination	Health care provider never	Provider never or sometimes sensitive to family's values/customs	Provider never or sometimes help respondent feel like a partner
Perceived amount of time affected by a given condition: Never (ref) vs. ever	2.5 (1.3–4.6)	4.3 (2.1–8.8)	4.1 (2.1–7.9)	4.7 (2.0–11.1)	4.2 (2.0–8.9)	4.8 (2.0–11.6)	6.7 (2.0–22.9)			7.4 (1.4–39.6)	4.1 (1.4–11.7)	3.0 (0.8–12.0)		
Ranking of severity of condition (low 0–3 ref)														
Moderate 4–7			2.0 (1.0–4.0)			1.8 (0.7–4.4)					4.6 (1.6–13.6)		1.8 (0.7–4.7)	3.4 (1.1–10.4)
High 8–10			2.4 (0.9–6.5)			1.6 (0.5–4.6)					18.6 (5.5–63.2)		3.50 (1.1–10.8)	2.1 (0.5–8.7)
Summary severity score (1-ref)														
2	37 (1.6–8.3)	1.6 (0.7–3.5)	1.1 (0.5–2.3)	1.7 (0.8–4.1)	3.5 (1.5–8.5)	1.8 (0.7–4.6)	4.1 (0.8–19.1)	1.3 (0.3–5.1)	0.7 (0.3–2.2)		1.6 (0.5–5.2)			
3	4.8 (1.9–11.9)	2.4 (0.9–6.1)	1.7 (0.7–3.8)	3.1 (1.2–8.0)	3.9 (1.4–11.1)	2.8 (1.0–8.3)	6.9 (1.3–37.6)	3.4 (0.7–16.0)	0.2 (0.03–1.7)		2.5 (0.8–8.3)			
4 or more	5.0 (1.7–14.7)	4.2 (1.5–11.8)	3.5 (1.2–10.4)	4.1 (1.4–11.7)	25.1 (7.4–85.3)	12.4 (3.8–40.4)	33.1 (6.3–174.2)	7.9 (1.8–36.1)	0.8 (0.2–3.1)		5.7 (1.6–21.6)			

Note. Logistic regression models adjusted for child age, child gender, child race, maternal education, family poverty level, child being uninsured within the past year, and the type of insurance (private or other).

Two specific applications for Alabama from this study are related to the definition of CYSHCN and the demonstrated need for professional care coordination for those children and youth with more severe conditions. The Maternal and Child Health Bureau and others have long advocated for a noncategorical definition for CSHCN while many state Title V programs, including Alabama's, use a categorical approach. The results of this study provide support for serving the children and families most severely affected by the child's special health care need which suggests giving consideration to abandoning a diagnosis-based admission criteria and move to one which is more tied to consequences, such as the screener used in this study. In tight budget times with large needs to meet these are not light considerations.

Assuring that children with complex medical needs receive adequate care coordination has been an ongoing concern for Alabama's CRS. This study's results reinforce the need for such coordination. The disease severity of CYSHCN can vary and have a profound effect on the day-to-day functioning of their families. It is critical for those in the Maternal and Child Health community caring for these children and youth to develop and support services and programs that are family-centered and pay special attention to the unique requirements of caring for youth with severe conditions. Further, recognition of the role that burden on the family plays in the access to and utilization of these services, independent of family characteristics, should also receive special attention. One approach to remedying the burden that families of CYSHCN in general experience, but, in particular for those families who care for a child or youth with a condition that requires much care in the home and the use of many healthcare and health-related services, is to assure that family-centered care is available to all CYSHCN in a medical home.

Family-centered care is associated with improvement in parents' satisfaction with services and decreased parental stress (22) and a medical home is designed to deliver such services in a coordinated manner.

Acknowledgments:
This research was supported in part by a contract with the Alabama Department of Rehabilitation Services, Children's Rehabilitation Service, and a training grant from the Maternal and Child Health Bureau (5 T76MC-00008-20 EDUCATION FOR MCH LEADERSHIP AT UAB).

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